Medicaid Program Evaluation

Working Paper

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THE MARYLAND MEDICAID WAIVER PROGRAM FOR PERSONS WITH DEVELOPMENTAL DISABILITIES: A CASE STUDY

Brian O. Burwell
SysteMetrics/McGraw-Hill

Department of Health and Human Services
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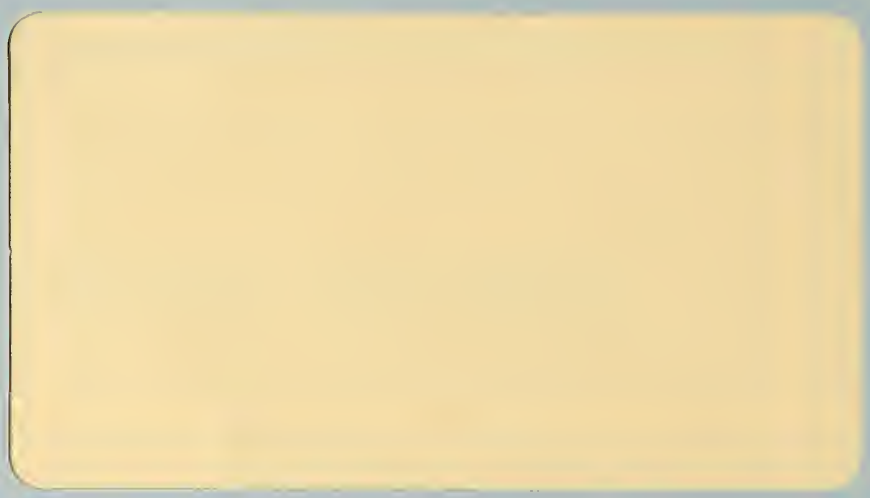

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Chapter 1

INTRODUCTION

Background

This report presents a case study of the Maryland Home and Community-Based Services Medicaid Waiver program for persons with Developmental Disabilities. The waiver allows the State of Maryland to receive Federal Financial Participation (FFP) under Medicaid for home and community-based services provided to persons with developmental disabilities that are not otherwise covered under the regular State Medicaid plan.

The Maryland Medicaid waiver program operates under the authority of Section 2176 of the Omnibus Budget Reconciliation Act (OBRA) of 1981. Under Section 2176, the Department of Health and Human Services may approve waivers to States for Medicaid coverage of certain home and community-based services provided to persons who are at risk of placement in long-term care institutions. The Home and Community-Based Medicaid Waiver Program, as it is generally known, is an attempt to address an institutional bias in Medicaid eligibility and service coverage policy.[1] Prior to enactment of the Section 2176 waiver authority, Medicaid coverage of long-term care services was largely restricted to care provided in institutional settings.

Although Home and Community-Based Medicaid waivers represent an expansion in the types of services which are eligible for Federal Financial Participation

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[1] Report to Congress: Studies Evaluating Medicaid Home and Community-Based Waivers. Department of Health and Human Services, Health Care Financing Administration, Office of Research and Demonstrations, December 1984.

under Medicaid,[2] waiver services are expected at the same time to be "cost-effective." States are expected to provide waiver services only to individuals who are otherwise at risk of placement in a Medicaid-certified long-term care facility. In Maryland, this means that persons provided waiver services are expected to otherwise be at risk of placement in an Intermediate Care Facility for the Mentally Retarded (ICF-MR), the cost of which would be covered by Medicaid. At the aggregate level, expenditures for waiver services are expected to be offset by reduced expenditures for ICF-MR care. In this manner, Medicaid waiver programs are expected to be "cost-effective."

The Home and Community-Based Medicaid waiver program has proven to be an extremely popular financing mechanism for States. Almost every State now operates at least one waiver program for either elderly, disabled, developmentally disabled, or chronically mentally ill persons; 37 States operate waivers for persons with mental retardation and other developmental disabilities. In FY 1987, total Federal/State spending for home and community-based services under the Medicaid waiver program had reached $505 million, of which $292 million (57.8%) were attributable to waivers for the developmentally disabled. Thus, at the national level, the Section 2176 waiver program represents a major policy expansion of the Medicaid service benefit package beyond the traditional "medically oriented" services that are normally covered by Medicaid.

The Maryland Medicaid Waiver: A Program Description

The Maryland waiver program for the developmentally disabled (DD) was originally approved by the Health Care Financing Administration (HCFA) with an effective date of February 12, 1984. In 1987, the Maryland Developmental Disabilities Administration (DDA), which administers the waiver program, applied and received a renewal of the original three-year waiver for an additional five years. The effective date of the renewed waiver was April 1, 1987, which was requested by Maryland to coincide with the fourth quarter reporting period of the State's fiscal year. The current waiver is effective until March 31, 1992.

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[2]Under Medicaid, Federal Financial Participation ranges between 50% and 77%, depending upon State per capita income. Maryland's FFP rate is 50%.

The Maryland DD waiver includes four basic service components:

- Residential Services. The waiver pays community-based providers for the cost of residential services provided to waiver clients. Most waiver clients reside in three-person residences called Alternative Living Units (ALUs), although others live in group homes housing four persons or more, while still others are placed in Individual Family Care (IFC), which is similar to foster care. The primary cost within this service category is the cost of the direct care staff in the client's residence. Various staffing models are employed in these residences, depending upon the service needs of the residents and the preferred staffing patterns of the provider agency. Also included within this service category are "consultant services," which include physical, speech, occupational, and behavioral management therapies provided directly or purchased by providers on an as-needed basis.

- Day Program Services. All waiver clients participate in some type of day program during the regular work week. Under the waiver program, the residential provider is the "lead" provider, who arranges for and sub-contracts with a day program provider for each waiver client. In some cases, the residential provider also operates the day programs for waiver clients, but in many cases residential services and day program services are provided by distinct agencies. In some cases, particularly in urban areas where there are multiple day program providers in the same geographic area, waiver clients served by the same residential provider may be served by three or four different day program providers.

- Transportation Services. Transportation services are arranged for and provided by the day program provider. Again, the day program provider may provide this service directly, or sub-contract with a transportation contractor. Since some waiver clients are non-ambulatory, they may require the use of specialized vans which can transport wheelchair-bound clients.

- Service Coordination. Service coordination is the "case management" component of the Maryland DD waiver. The Developmental Disabilities Administration contracts directly with various agencies to provide service coordination for waiver program recipients. In the Southern and Eastern regions of the State, service coordination is provided by county health departments. In the Central and Western regions, service coordination is provided by a private agency, the Frederick County Association for Retarded Citizens.

Client Eligibility

Maryland's is one of the few Medicaid waiver programs for the developmentally disabled which is exclusively targeted to "deinstitutionalized" clients. Only clients in one of Maryland's eight State Residential Centers, its publicly-operated ICFs-MR, are eligible for placement in the waiver

program. First, persons living in the State Residential Centers (SRCs) who are assessed as candidates for community placement under the waiver are placed on a list. The Developmental Disabilities Administration then issues a Request for Proposals for a specific number of clients to be served under the waiver (several rounds of RFPs have been implemented since the start of the waiver in 1984).

Community-based residential providers usually visit the SRCs to interview and assess waiver candidates, then submit proposals to serve specific clients. Generally, providers submit proposals to serve clients residing in an SRC which is located in their own geographical region, although it is entirely possible to submit proposals for clients living in other SRCs as well. Proposals are generally submitted in units of three clients, or a single Alternative Living Unit (ALU). In essence, the proposal contains the provider's estimate of starting up and operating a new Alternative Living Unit to serve three waiver clients. The proposal includes proposed staffing arrangements and salaries, fringe, facility costs, consultants' fees, room and board costs, day program costs, and administrative costs.

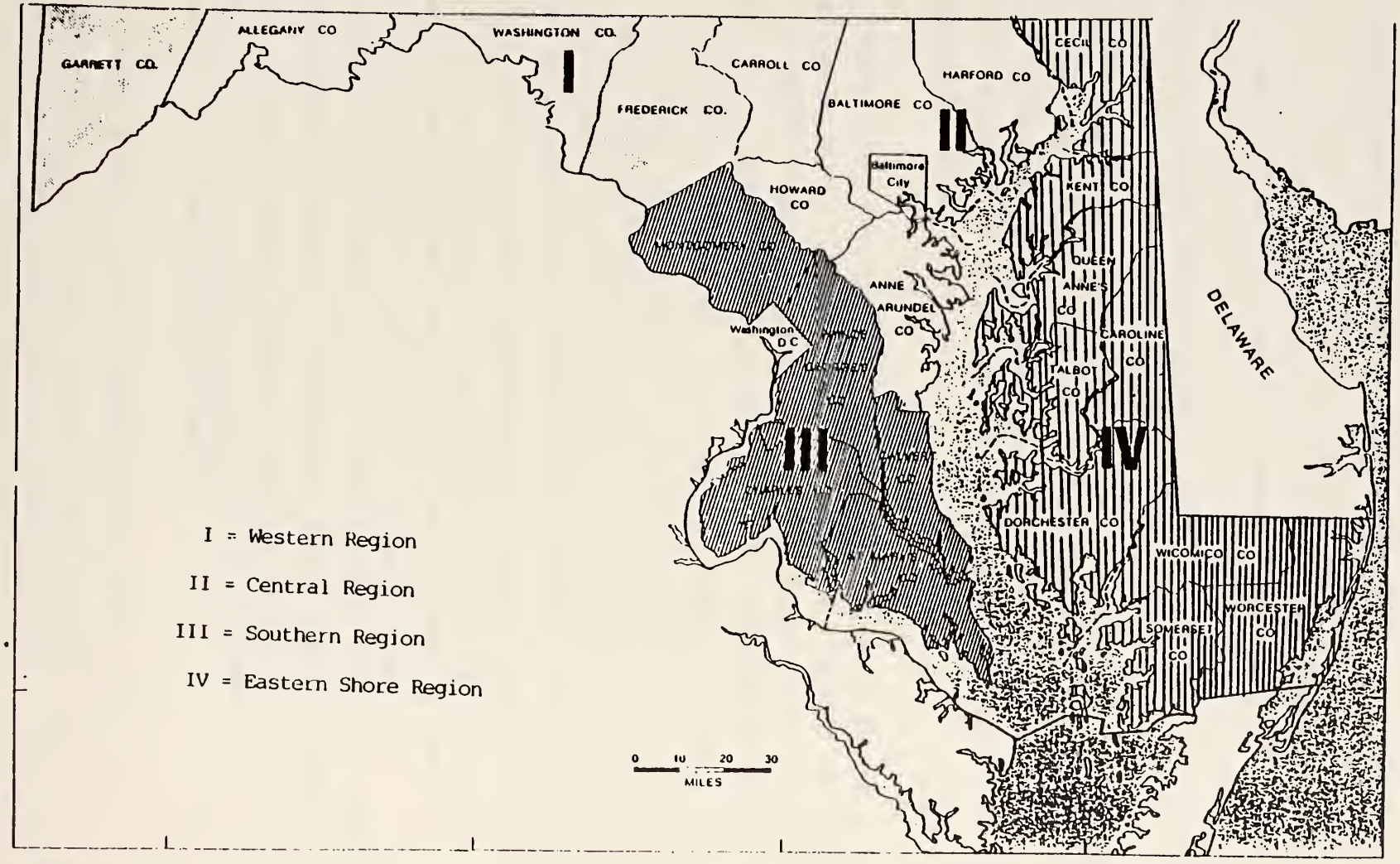
In developing proposals, providers attempt to identify three clients who they think would make appropriate housemates, and who could live together compatibly. In some cases, the clients themselves identify other friends in the SRC with whom they would like to live in the community. Although providers identify specific clients in their waiver proposals, there is no assurance that they will actually get the clients they have bid on. Sometimes multiple providers bid on the same clients, so that there is some shuffling of clients between the proposal process and actual placement.

After submission of a proposal, a negotiation process occurs between the provider and DDA. In general, these negotiations take place between providers and the four Regional Offices of DDA (see Exhibit 1-1 for a map of the four State regions). Thus, the rate paid by DDA to serve waiver clients is basically a negotiated rate between the State and the provider.

Once a proposal is accepted, DDA awards the provider a start-up grant to develop the new residential facility. This includes money to find, rent, and

Exhibit 1-1

The Four Service Delivery Regions of the
Maryland Developmental Disabilities Administration



furnish a new ALU, money to recruit and hire direct care staff, and money for various other start-up costs. Once the residence is available, a gradual transition process for waiver clients is instituted. Provider staff will often visit the client in the SRC to acquaint themselves with the client. The client may then come visit the residence for a meal or a weekend. Then a placement date may be set, and the client is prepared to make the permanent move. In many cases, waiver clients have lived at the SRC for the majority of their lives, and the transition from the institution to the community is a traumatic one. There is often a considerable amount of coaxing which has to be done during this transition. If the client has family who are still involved in his or her life, the anxieties of the family about community placement often have to be addressed as well.

Once clients have been placed in the community residence, the provider's operational grant begins. The payment system employed by DDA in the Medicaid waiver is a "grants payment," system, the same system which the State has traditionally employed to fund all community-based residential providers, even prior to the waiver. Providers are paid quarterly grants for each residential program, in advance, in accordance with the negotiated grant amount. Providers are required to submit quarterly cost reports, which show the actual costs of operating the program versus the negotiated cost. At the end of the fiscal year, there is a reconciliation process between the amount of funds received by the provider through the grants system and their actual costs. Providers rarely operate their programs at a lower cost than what they originally negotiated with DDA. The more usual case is for providers to submit supplemental budget requests for costs that were unanticipated or underestimated in the original proposal. DDA reviews and approves these supplemental budget requests on a case-by-case basis, which are paid with discretionary funds. However, providers know that the amount of discretionary funds available to DDA is limited, and generally operate their programs at levels close to their negotiated grant amount.

Once awarded, grants are not renegotiated each fiscal year. All residential providers, both waiver and non-waiver, receive the same inflationary increases each fiscal year, as approved in DDA's budget by the legislature.

Quality Assurance Mechanisms

Maryland employs a multi-tiered quality assurance system in the DD waiver program. First, Service Coordinators serve as outside client advocates, who visit the client at least every other month, monitor the provider's implementation of the Individual Program Plan (Plan of Care), and advocate for services. Second, DDA contracts with the Delmarva Foundation, the Peer Review Organization in Maryland, to conduct annual re-certifications of the client's eligibility for the waiver and to assure that the client is receiving active treatment. Since all waiver providers are Medicaid providers, they are also monitored annually by the Medical Assistance Compliance Administration through Inspection of Care teams. The teams make annual reviews of all waiver clients to ensure that the care provided to clients meets Medicaid regulations for service quality. Fourth, all residential programs must be licensed and certified by DDA. Licensing and certification teams make annual visits to inspect residential facilities and certify that programs are being operated in compliance with DDA regulations. If licensing and certification procedures identify problems at a particular provider agency, Regional Office staff may also get involved in doing follow-up monitoring to ensure that problems are being corrected. If problems continue to persist, Regional Office staff may also be placed in the provider agency on a temporary basis until deficiencies are satisfactorily resolved. Finally, most residential program providers are monitored by their local county governments, to ensure that their facilities and programs comply with local fire, safety and health codes.

Purpose and Organization of Report

The purpose of this report is to provide a brief overview of Maryland's waiver for persons with developmental disabilities.[3] The Maryland waiver was selected for a case study because it is one of the few waivers for the developmentally disabled which is exclusively targeted to deinstitutionalized

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[3]Most persons with developmental disabilities are mentally retarded. However, the developmentally disabled also include persons with cerebral palsy, autism, epilepsy, and other developmentally-related conditions.

clients. In most waivers for the developmentally disabled, persons living in the community who have never been institutionalized are also eligible for waiver services if they are determined to be at risk of institutional placement. Because Maryland's waiver exclusively serves persons being deinstitutionalized from State-operated facilities, the waiver population in Maryland is more severely disabled, on average, than waiver populations served by most other States. It has also had a markedly different impact on the community-based provider system than most other waiver programs for persons with developmental disabilities.

The primary source of information for the study was in-person interviews with State officials in the Maryland Developmental Disabilities Administration (DDA) and with local residential providers of waiver services. On-site interviews were conducted with Executive Directors and Residential Program Directors of 15 of the 40 residential providers currently participating in the waiver program. These providers account for 424 (59%) of the 716 clients presently served under the waiver. Executive Directors of three of the six Service Coordination contractors were also interviewed during the study. Financial and statistical data were also provided by DDA on various aspects of the waiver program and of the Maryland MR/DD service system in general. Annual Medicaid statistical data (HCFA 2082 data) on ICF-MR utilization and expenditures were also utilized in the analysis.

The primary objective of this report is to provide readers with a discussion of the some of the major policy issues which have emerged during the implementation of the Maryland DD waiver program over its first four years. The Section 2176 waiver program represents HCFA's first introduction to the financing and management of non-institutional service systems for persons with developmental disabilities. The nature of this service system, and the policy issues associated with it, differ considerably from the issues associated with HCFA's management of the ICF-MR program. Further, it is likely that Medicaid financing of non-institutional services for the developmentally disabled will continue to expand in the future, either under the authority of the Section 2176 waiver program itself, or under a more permanent financing mechanism. In any case, it is apparent that HCFA will become increasingly involved in managing both the cost and quality of community-based services for the developmentally disabled under the Medicaid program over the coming decade.

Following this introductory chapter, Chapter 2 provides an overview of the implementation of the Medicaid waiver program in Maryland from 1984 through the present. The implementation of the waiver is described within the context of the entire State MR/DD service system during this period. Medicaid waiver programs are but one factor affecting the development of community-based service systems for persons with developmental disabilities, and any evaluation of Medicaid waivers must be conducted in the context of the other factors which are also affecting the MR/DD service system. Chapter 3 then provides a discussion of a selected set of policy issues which are presently affecting the Medicaid waiver program in Maryland. This discussion is not meant to be evaluative or judgmental. Rather its purpose is to highlight some of the current challenges and problems faced by the State of Maryland in its management and development of Medicaid-financed community-based care for the developmentally disabled.

Chapter 2

IMPLEMENTATION OF THE MARYLAND MEDICAID WAIVER PROGRAM FOR THE DEVELOPMENTALLY DISABLED

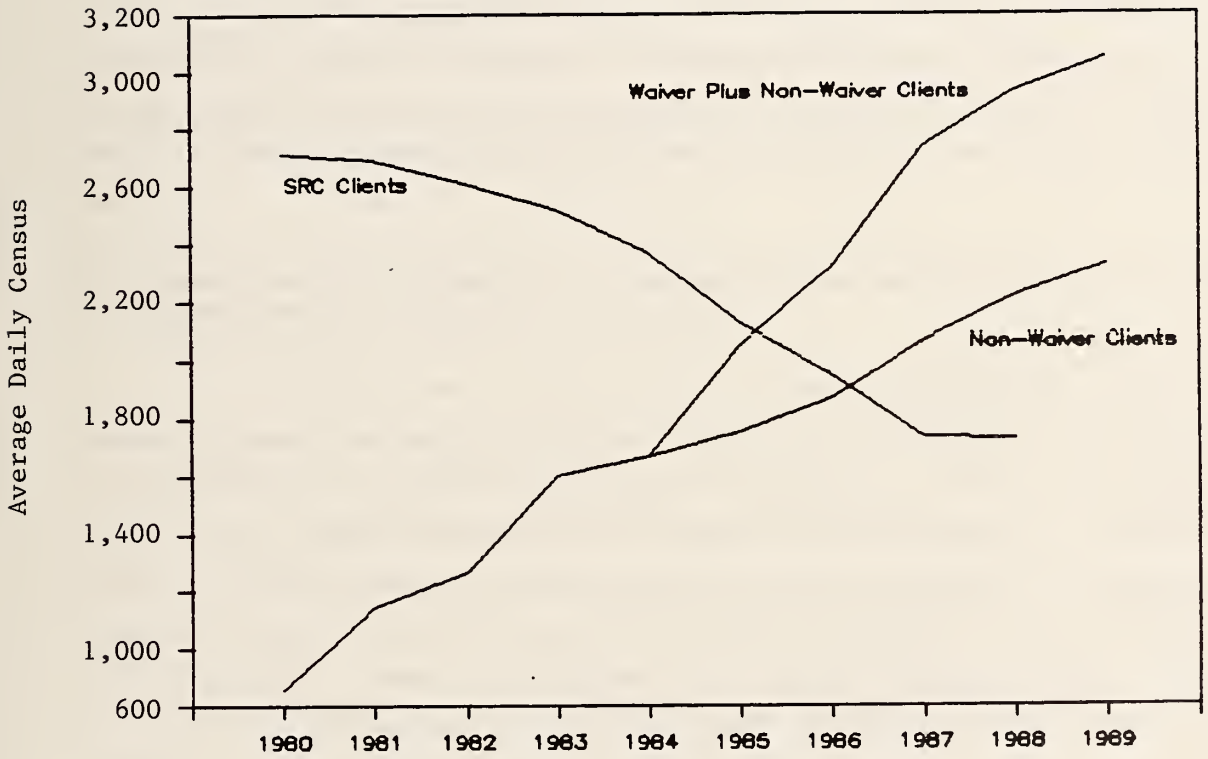
The Maryland Medicaid waiver program has been part of a major shift in the State's overall service system for persons with developmental disabilities from an institutionally-based services system to a community-based services system. As shown in Exhibit 2-1, there were only 656 mentally retarded persons in community-based residential programs in Maryland in 1980, and over 2,500 persons in the State Residential Centers (SRCs). By 1988, the average daily census of the SRCs had declined by 39%, to 1,533 clients, while the number of persons living in community-based residential programs had increased 358% to 3,007 clients. Put otherwise, 79% of the residential population in Maryland was cared for in institutions in 1980. By 1988, the percentage of residential placements served in institutions as opposed to community-based programs was only 34%.

How important a factor was the Medicaid waiver program in the shift toward community-based services in Maryland?

The Medicaid waiver program has been an important factor, but only one factor in this shift in the Maryland MR/DD service system. Even before the Medicaid waiver program had been approved by Congress, Maryland had begun a major expansion in its community-based residential system. Funding for community-based residential programs had increased from $3.5 million in FY 1980 to $14.5 million in FY 1984, the year in which the waiver program was first implemented. The SRC population had already begun to decline, and the State had already been able to close one small 60-bed facility in 1982. Thus, the opportunity for Maryland to secure Federal funds to expand community-based programs for the developmentally disabled under the waiver came at a time when it had already embarked upon a significant community services expansion effort.

Exhibit 2-1

Average Daily Census of State Residential Centers and Community-Based Residential Programs (Waiver and Non-Waiver): 1980-1988



Source: Developmental Disabilities Administration, Maryland Department of Health and Mental Hygiene, 1988. Figures for 1988 and 1989 are estimated.

Another factor in the shift was pressure placed upon the State by the Federal government. The United States Department of Justice had initiated a class action suit against the State of Maryland on behalf of the clients being served in the Rosewood Center, Maryland's largest SRC, which in 1983, had an average daily population of 1,204 clients. The suit cited deficiencies in programming, staffing, client abuse and neglect, environmental conditions and inappropriate placement. In February of 1983, the State signed a consent decree, which stipulated a 40% reduction of the Rosewood Center population through placements in community-based residential settings over a three-year period, and a corresponding increase in staffing ratios, programming, and environmental quality at Rosewood. Although the waiver program was itself part of the consent decree, Maryland applied for and used the Medicaid waiver as a means to finance the deinstitutionalization objectives set forth in the consent decree.

What impact has this expansion in community-based services had on the supply of community-based residential providers?

In the last four years, there has been a major expansion in the supply of community-based residential provider agencies in Maryland. By law, all of these agencies are private not-for-profit agencies. Prior to the waiver program, the community-based service system was dominated by a relatively small number of large agencies, which operated both day programs for developmentally disabled clients living at home and residential programs funded through all-State funds. Local Associations for Retarded Citizens (ARCs), located in each county, constituted the largest segment of the community-based provider network.

When the waiver program was first implemented, there was a proliferation of new provider agencies in the State. Some of these agencies were spin-offs of existing agencies, in which second-level managers of existing providers saw the opportunity to form their own agency, and secured their initial "business" by bidding on waiver clients. In other cases, agencies which had only operated day programs decided to expand into residential services by participating in the waiver program. In still other cases, agencies which operated in other States established new agencies in Maryland.

DDA encouraged the establishment of new provider agencies under the Medicaid waiver program. Although the immediate objective was to meet waiver targets for community placements, a secondary objective was to "broaden the base" of community-based providers with whom DDA could contract for services. The formation of new providers was also essential to meeting waiver program targets, since many existing providers were not willing, or capable, of growing at the rate it would have required to serve the projected waiver population.

In consequence, the community-based provider network has grown from a small number of residential program providers prior to the waiver to a current supply of 67 agencies across the State providing residential services in community-based settings to waiver and/or non-waiver clients. Of these 67 agencies, 40 participate in the waiver program, and 27 serve non-waiver clients only. Of the 40 agencies participating in the waiver, 35 operate programs for both waiver and non-waiver clients, and 5 serve waiver clients exclusively.

This growth in the supply of community-based provider agencies is one of the important policy issues in the Maryland Medicaid waiver program, and is discussed further in Chapter 3. As a result of this growth, the character of the community-based provider network has changed dramatically over the last four years. A major issue is to what extent this growth in supply has affected the quality of community-based care for persons served under the waiver.

Has the growth of the waiver program met original projections?

In approving Medicaid waivers, HCFA places limits on the number of waiver recipients who can be served in each waiver year, and on the total amount of expenditures which States may claim for waivered services. Exhibit 2-2 presents the HCFA-approved limits for Maryland's DD waiver program for the eight years for which the waiver has been approved (1984 through 1992) and actual recipients and expenditures for the first four years of the waiver's operation.

In terms of recipients, Maryland's waiver population has grown relatively close to the HCFA-approved limits. There are currently 716 clients being served in the waiver program, compared to an approved limit of 868 recipients.

Exhibit 2-2

Approved and Actual Growth in the Maryland DD Waiver Program

Waiver Year	Recipients		Expenditures	
	Approved	Actual	Approved	Actual
1 (1984-85)	295	304	$ 6,790,310	$ 3,617,719
2 (1985-86)	497	415	$12,123,092	$ 9,093,423
3 (1986-87)	716	642	$23,264,988	$13,515,339
4 (1987-88)	868	716	$31,369,520	$25,000,000*
5 (1988-89)	1,018		$39,727,414	
6 (1989-90)	1,172		$49,115,004	
7 (1990-91)	1,291		$57,843,255	
8 (1991-92)	1,355		$64,588,785	

Sources: Maryland waiver applications and HCFA 372 reports.

*estimated

However, Maryland's expenditures for waiver services have lagged considerably behind its original projections, for two major reasons. First, there have been considerable delays in getting new residential programs started. Maryland cannot begin claiming for waiver services until a recipient is actually moved from the institution to the community. Providers encountered all of the usual problems of finding and leasing appropriate residences, hiring staff, preparing the client for transition to the community, and so on. Projected expenditure levels assumed that all clients would receive a full year of waiver services, when, in actuality, recipients received waiver services for less than a full year.

One measure of these delays in program start-up is the average number of days which waiver clients were enrolled in the waiver program in a given year. These data are available on Maryland's HCFA 372 reports, which report total recipients served during the year and total days of waiver coverage. In the first year, waiver recipients were in the program an average of only 182 days, exactly half a year. Thus, expenditures for waiver services in the first year really reflect only a half year of coverage. The average number of waiver-covered days for recipients served in the second year was 254 days, and in the third year, 236 days. The average declined in the third waiver year because Maryland had implemented a new wave of community placements, and delays in program start-up again reduced the average time which waiver recipients were served in the community.

The level of expenditures for waiver services has also been less than projected because Maryland is unable to claim certain costs for waiver clients served in the program. First, because the residential model most frequently employed in the Maryland Medicaid waiver program is the three-person Alternative Living Unit, Maryland pays higher room and board costs for waiver clients than most other States, where waiver clients generally live in larger residential facilities. For example, in FY 1988 awards made to waiver providers under the DDA grants payment system, $3.5 million of the $27.5 million in total grant awards (12.7%) were for room and board costs. These costs are not eligible for Federal Financial Participation. The average annual cost per waiver recipient for room and board costs was $4,826. Room and board costs in most waiver programs are almost totally financed by client SSI

contributions (the reason why they are not recoverable through FFP). In Maryland, cclient contributions cover only 61% of these costs. Therefore, in FY 1988, Maryland paid $1.3 million in room and board costs for waiver clients from 100% State funds.[1]

Further, Maryland can only receive FFP for days on which waiver clients actually receive waiver services. If clients go "on leave" from their residential program to visit with their families on weekends or holidays, go on vacation, or are temporarily placed in an in-patient facility, the State does not receive FFP for the days for which the client was out of the program. Providers submit "invoices" to DDA, showing attendance records of their waiver clients in their residential programs. (These are not real invoices since providers are paid quarterly through the grants payment system; they are only used as documentation in claiming FFP). Turnover among waiver clients also creates vacancies in waiver-funded residential programs (e.g. if a waiver client must be re-institutionalized and another community placement of an institutionalized client made). Since these client leave days and vacancies do not reduce the real cost to providers of operating residential programs, DDA still pays providers for the cost of these days. In FY 1987, DDA estimates that it paid waiver program providers about $500,000 for days which were not eligible for FFP under the waiver.

Currently, the Maryland DD waiver is operating about one year behind its original projections. In its approved waiver renewal, Maryland projected making another 160 placements in the first year of the new waiver (April 1987 through March 1988). For a number of reasons, Maryland chose not to move ahead with these community placements, and only placed clients to fill existing program vacancies. However, it presently intends to place these additional 160 clients in two phases in FY 1989. In the first phase, Maryland plans to place an additional 72 clients, and close another building at the Great Oaks Center by the end of the fiscal year (June 1989). In the second phase, DDA plans to

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[1]Waiver clients are allowed to keep $100 of their SSI income each month for personal expenses and must contribute the remainder of their income towards room and board costs. Since waiver clients are not eligible for State Supplementation Payments (SSP) in Maryland, the general rule is that clients keep $100 of their Federal SSI benefit of $354 per month, and contribute $254 towards room and board.

place an additional 88 clients into the waiver, and close another SRC, the Highland Health Facility, by the end of the same year.

What are the characteristics of persons served under the Medicaid waiver program in Maryland compared to waiver recipients in other States?

Waiver recipients in the Maryland DD waiver program are, on average, more severely disabled than waiver recipients in other States. They are also somewhat older, as shown in Exhibit 2-3. In Maryland, only 4.3% of waiver recipients are children under age 21, compared to 20.5% of all DD waiver recipients. On the other hand, 44.7% of all waiver recipients in Maryland are over the age of 40, compared to 25.0% of DD waiver recipients nationally. Maryland also serves a higher proportion of male recipients (63%) than the national average (56%).

Exhibit 2-3

Age Distribution of Waiver Clients in Maryland Compared to All DD Waiver Programs

Age	Maryland	All DD Waivers
0 - 14	0.9%	9.9%
15 - 21	3.4%	10.6%
22 - 39	50.9%	54.5%
40 - 64	39.4%	22.8%
65+	5.3%	2.2%
Total	100.0%	100.0%

Sources: Third Annual Survey of Section 2176 Home and Community-Based Medicaid Waiver Programs conducted by La Jolla Management Corporation, 1987. Data reflect waiver program caseloads as September 30, 1986. Data for all waiver recipients reflect data received from 25 of 38 DD waiver programs who were able to provide age distribution data on their waiver populations.

A much higher percentage of waiver recipients in Maryland also have a diagnosis of mental retardation in the severe to profound range than

developmentally disabled recipients in other States, as shown in Exhibit 2-4. In Maryland, almost 77% of all waiver recipients had a diagnosis of mental retardation in the severe to profound range, compared to an average of 49% in all waiver programs for the developmentally disabled. As also shown in Exhibit 2-4, the distribution of waiver recipients by level of retardation in Maryland more closely resembles the overall distribution of residents of State-operated residential facilities than it resembles that of other State waiver populations.

Exhibit 2-4

Level of Retardation of Waiver Recipients in Maryland Compared to All DD Waiver Recipients and Residents of State-Operated Residential Facilities

Level of Retardation	Maryland Waiver Recipients	All DD Waiver Recipients	Residents of State-Operated Facilities
Mild	7.9%	21.9%	7.1%
Moderate	15.2%	29.5%	11.4%
Severe	31.5%	28.2%	22.5%
Profound	45.4%	20.4%	59.1%
Totals	100.0%	100.0%	100.0%

Sources: Third Annual Survey of Section 2176 Home and Community-Based Medicaid Waiver Programs conducted by La Jolla Management Corporation, 1987 and University of Minnesota, Persons with Mental Retardation in State-Operated Residential Facilities. Data for waiver recipients reflect caseloads as of September 30, 1986. Data for residents of State-operated facilities reflect residents as of June 30, 1985. Data for all DD waiver recipients reflect data from 25 of 38 DD waiver programs who were able to provide data on level of retardation for their waiver populations.

Waiver recipients in the Maryland DD waiver program also have significant deficits in activities of daily living. According to survey data reported by Maryland, 7.4% of waiver clients are not toilet trained, 14.3% cannot walk without assistance, 62.5% cannot dress without assistance, and 37.2% cannot communicate verbally.

What impact has the DD waiver had on ICF-MR utilization and expenditures in Maryland?

It is difficult, if not impossible, to establish a causal relationship between the Medicaid waiver and subsequent ICF-MR utilization and expenditure trends. This is due to the fact that even if Maryland had not secured the waiver from HCFA to receive Federal Financial Participation for the cost of community placements, Maryland would still have had to comply with the terms of the consent decree with the U.S. Department of Justice. Without the waiver, Maryland may have pursued other alternatives, such as developing small-scale ICFs-MR, or investing more of its resources in improving conditions at Rosewood Center. It would probably not have been able to finance the community services expansion which occurred under the waiver with all State funds.

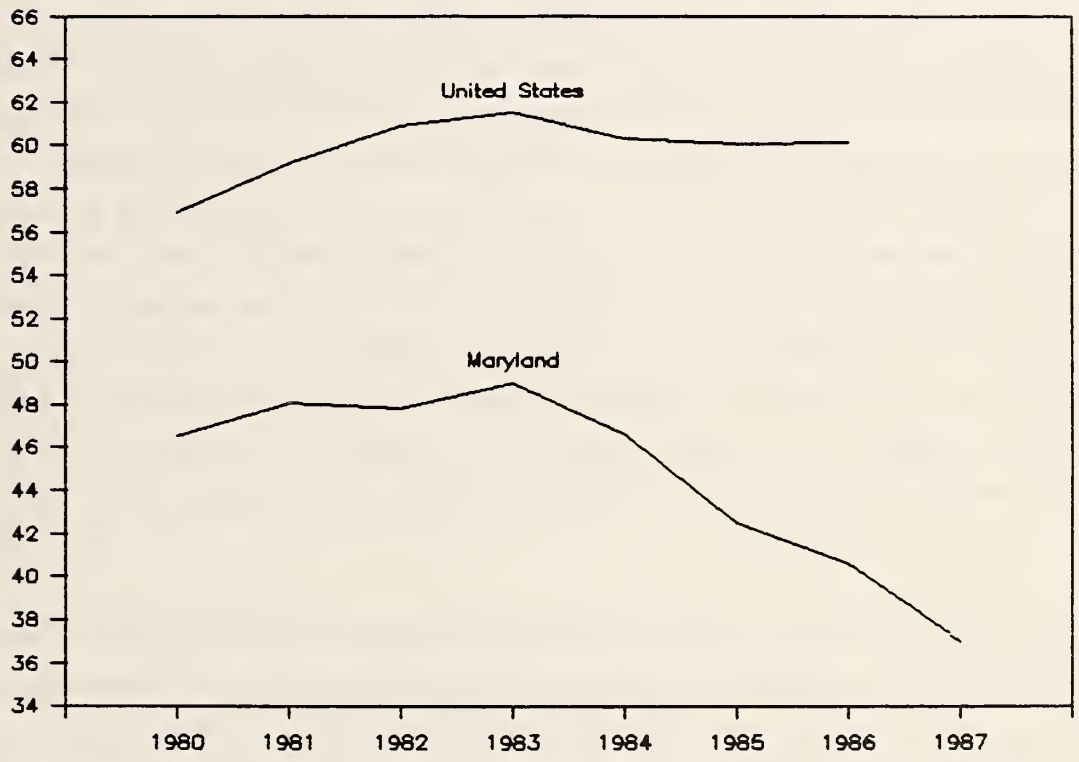
In any case, it is clear that the community placements made under the Medicaid waiver program have had a substantial impact on reducing ICF-MR utilization and expenditures in Maryland. In 1984, the year in which the waiver program was implemented, the average daily population in Maryland's State Residential Centers stood at 2,168. Since that time, 716 of these persons (33%) have been placed in community-based residential programs under the waiver. Today, the average daily population of the SRCs stands at 1,533, a net reduction of 635 recipients.

As shown in Exhibit 2-5, Maryland's ICF-MR utilization rate is now considerably below the national average. Even prior to the waiver, the number of ICF-MR recipients per 100,000 population in Maryland was already below the national average. In 1984, there were 47 ICF-MR recipients per 100,000 population in Maryland, compared to 60 recipients per 100,000 population nationwide. Since 1984, the national ICF-MR utilization rate has remained flat. In Maryland, the ICF-MR utilization rate declined to 37 recipients per 100,000 population, a 21% reduction.

Medicaid expenditures for ICF-MR services have also declined (in real dollars) since the waiver program was implemented. Between 1984 and 1987, ICF-MR expenditures in Maryland increased from $60.6 million to $65.5 million, an increase of 8.1%. In the United States as a whole over the same period,

Exhibit 2-5

ICF-MR Recipients Per 100,000 Population:
United States and Maryland



Source: HCFA 2082 data, Bureau of Data Management and Strategy.

ICF-MR expenditures increased from $4.3 billion to $5.5 billion, an increase of 28.9%. In inflation-adjusted dollars, ICF-MR expenditures actually declined by 10.5% in Maryland over this three-year period, while nationwide, expenditures increased by 6.2% in real dollars.[2]

Given that the average daily population of the State Residential Centers in Maryland has declined by 30% since 1984, why have ICF-MR expenditures declined by only about 10% in real terms? There are two primary reasons. One is that the waiver has had less of an impact on ICF-MR utilization than on total utilization of SRCs. When the waiver was implemented in 1984, Maryland still had a number of licensed beds in its SRCs which were not ICF-MR certified beds. Although Maryland had been working to reduce the number of uncertified beds in its SRC system prior to the waiver, there were still a number of beds which did not meet ICF-MR standards of care. Although all persons placed into the waiver program were in an ICF-MR certified bed prior to placement, in some cases the placement of an ICF-MR recipient into the community was followed by a transfer of another SRC recipient from an uncertified bed to a certified one. The result of this process was a more steep decline in the number of total SRC beds than in the number of persons in ICF-MR certified beds, as shown in Exhibit 2-6.

The second reason why ICF-MR expenditures have not declined more rapidly is that reductions in utilization do not necessarily translate into reductions in costs. Although the population of the SRCs have declined considerably, it is also true that the fixed costs of operating the SRCs have become spread over fewer clients. The result is that average costs per ICF-MR recipient in Maryland have increased substantially, as shown in Exhibit 2-7. In 1984, the average annual cost per ICF-MR recipient in Maryland was almost exactly the same as the national average, at $29,951. By 1987, Maryland was spending an average of $38,986 per recipient, about 6.4% higher than the average spent in all other States.

To some extent, higher costs per ICF-MR recipient in Maryland reflect the higher cost of serving a residual population with higher service needs than the ICF-MR population served in other States. Yet despite the increased resources being spent on the recipients who remain in Maryland's SRCs, the State is

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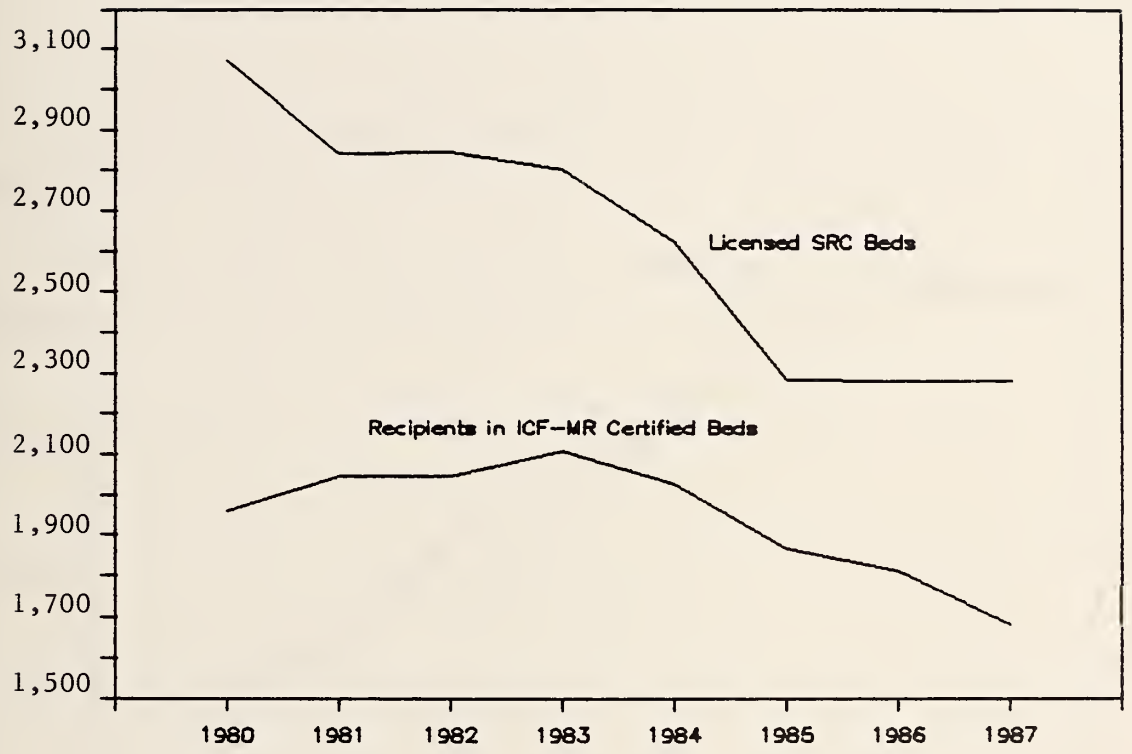
[2]Expenditures were adjusted for inflation using the medical care component of the Consumer Price Index for all urban consumers. Source: Social Security Bulletin, Vol. 51(1), January 1988, Table M-39.

Exhibit 2-6

Number of Licensed SRC Beds and Number of Recipients in ICF-MR Certified Beds: 1980-1987

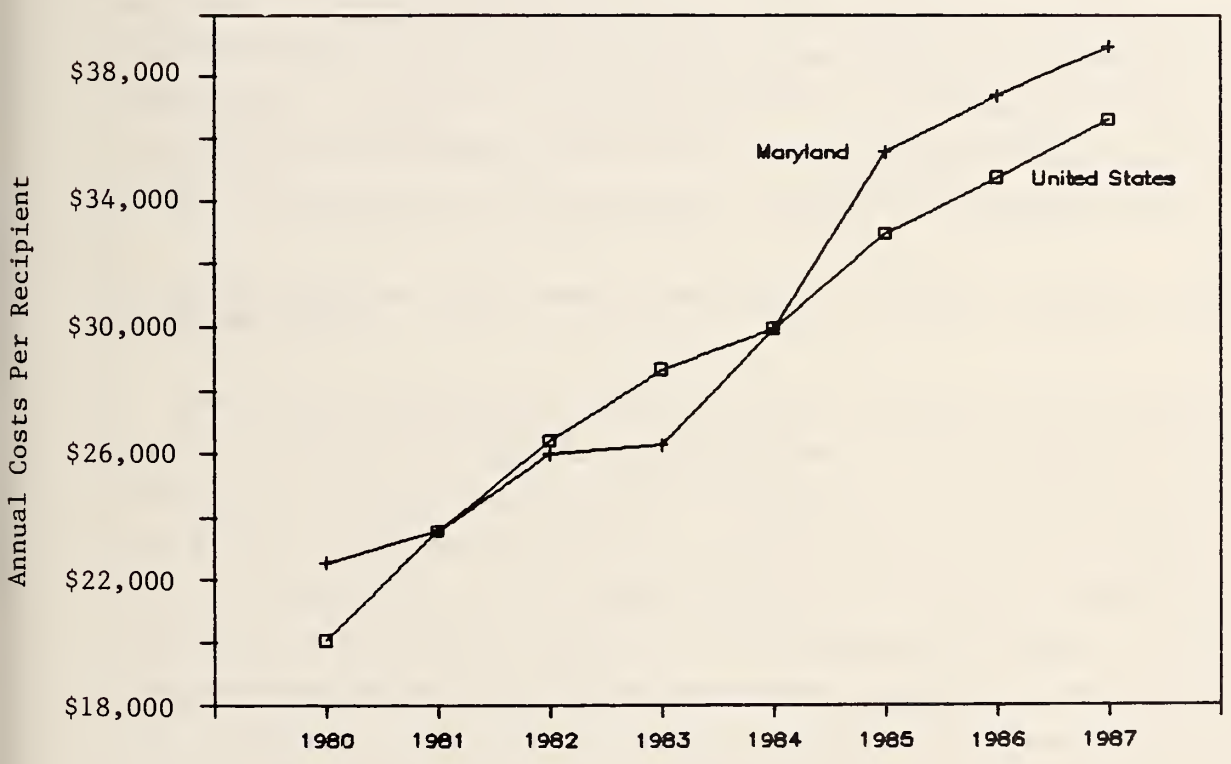


Source: Developmental Disabilities Administration, Maryland Department of Health and Mental Hygiene, and HCFA 2082 data, Bureau of Data Management and Strategy.

Exhibit 2-7

Average Annual Costs Per ICF-MR Recipient:

United States and Maryland



Source: HCFA 2082 data, Bureau of Data Management and Strategy.

having continuing problems maintaining Federal certification of its ICF-MR beds. In February of 1988, the Health Care Financing Administration notified Maryland that conditions at the Rosewood Center, Maryland's largest SRC "posed an immediate and serious threat to the health and safety of residents." Deficiencies cited by HCFA included the lack of an operational system for analysis and follow-up of incident and injury reports, abusive treatment of residents by other residents and by themselves, insufficient staff for control and discipline of residents, and overly hot water temperatures in resident bathrooms. Maryland responded to this threat of de-certification of the Rosewood Center with a corrective action plan, which was implemented immediately. In April of 1988, HCFA surveyors re-visited the facility and rescinded the threatened termination of ICF-MR certification of the entire Center, although one of the cottages at the Center was de-certified.

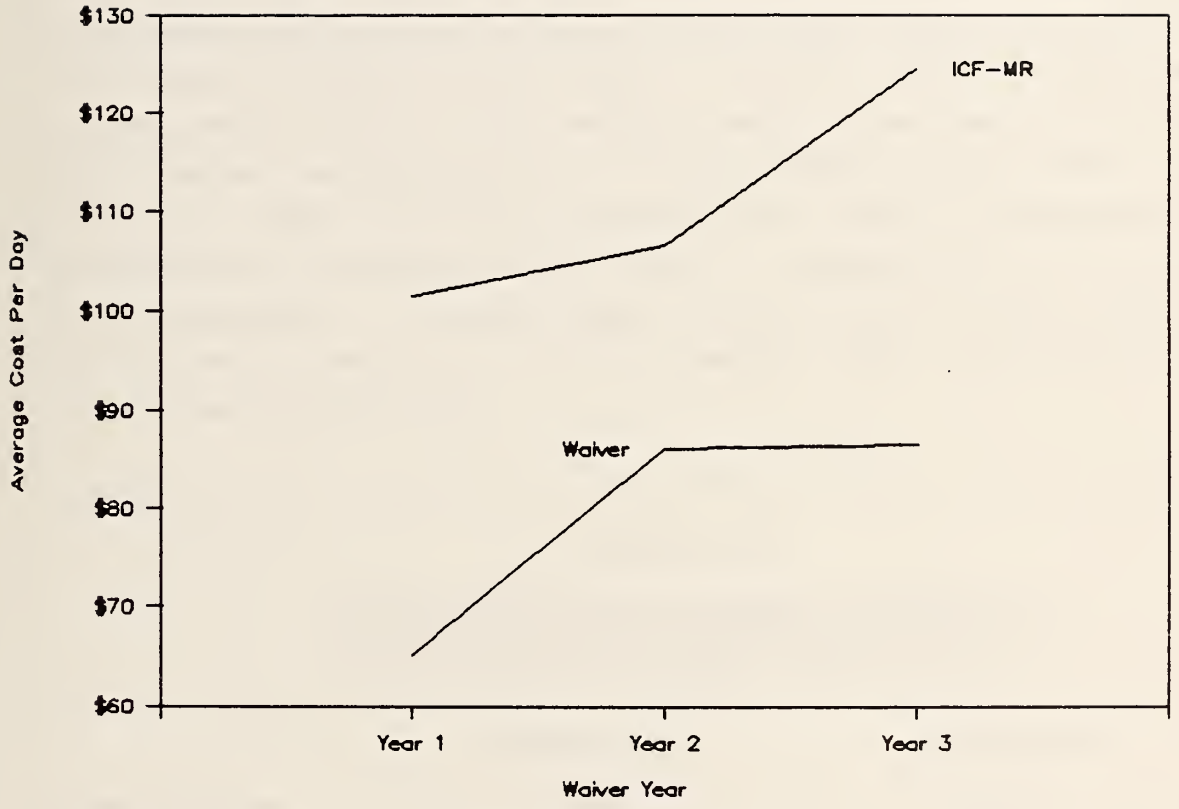
How do Medicaid and total Federal costs under the waiver compare to the costs of ICF-MR care?

Comparing average annual costs for waiver recipients with average annual costs for ICF-MR recipients is misleading due to client movement in and out of both types of service arrangements. As previously discussed, waiver clients may be in an ICF-MR for part of the year, then placed in the community for the rest of the year. Also, the waiver will not pay for days in which the waiver client is not residing in a waiver-covered residential program. In brief, average annual costs do not adjust for varying lengths of participation in each type of service. Thus, a more accurate comparison is to compare the average daily cost of ICF-MR care to the average daily cost of waiver-covered care.

These data are provided in the annual HCFA 372 reports, on which States report total expenditures for waiver and ICF-MR care per waiver year and also total days of coverage for both types of services. Data provided on Maryland's HCFA 372 reports for the first three years of the waiver (February 1984 though February 1987) are presented in Exhibit 2-8. In the first year of the waiver, the average daily cost per waiver client was $65.22, 64% of the average daily cost of ICF-MR care, which was $101.44. In the waiver's third year, the average daily cost per waiver client had risen to $86.43, 69% of the average daily cost of ICF-MR care, which was $124.43.

Exhibit 2-8

Average Medicaid Cost Per Day of
Waiver-Funded Care and ICF-MR Care:
Waiver Years One to Three



Source: Maryland HCFA 372 Reports. Waiver Year One: February 13, 1984 through February 12, 1985; Waiver Year Two: February 13, 1985 through February 12, 1986; Waiver Year Three: February 13, 1986 through February 12, 1987.

These figures do not represent the actual total State and/or Federal costs of serving clients in both types of service arrangements. For most waiver clients, the Federal government also pays Supplemental Security Income (SSI) benefits. In 1986, the third year of the waiver, the Federal SSI benefit level was $336.00 per month. Assuming that all waiver clients were eligible for the full benefit level, this would add an additional $11.05 to the daily cost of care paid entirely by the Federal government.[3] As previously discussed, the State also incurs additional costs for waiver clients which are not recoverable through the waiver. These include room and board costs not covered by client SSI payments, and the costs for days on which waiver clients are absent from their community program, for one reason or another. These unrecovered amounts add about another $9.50 in daily costs for waiver clients paid entirely by the State. The only additional cost for ICF-MR recipients is the Federal cost of SSI payments. Since ICF-MR recipients are only eligible for SSI benefits of $25 per month, SSI payments only add $0.82 to the average daily cost of ICF-MR care. Estimated total State and Federal costs per day for waiver clients and ICF-MR clients in the third waiver year (February 1986 through February 1987) are presented in Exhibit 2-9.

Exhibit 2-9

Estimated Daily Cost For Waiver Care and For ICF-MR Care in Waiver Year Three: (1986-87)

	Waiver Care	ICF-MR Care
Waiver Services	$86.43	$ 0.00
ICF-MR Services	0.00	124.43
Federal SSI payments	11.05	0.82
Unrecovered costs	9.50	0.00
Total	$106.98	$125.25
Total Federal	54.27	63.04
Total State	52.71	62.21

Source: Maryland HCFA 372 reports, and data provided by Maryland Developmental Disabilities Administration on unrecovered costs.

[3] Actually, only about 80% of waiver recipients receive SSI. However, the primary source of income for clients who do not receive SSI benefits is Social Security Disability Insurance (SSDI), also paid by the Federal government.

There are still other State and Federal costs for waiver clients and ICF-MR clients not included in Exhibit 2-9, for which data are not available. Some waiver clients may receive Food Stamps, Section 8 housing subsidies, and other Federal benefits not included in the figures cited above. Further, Exhibit 2-9 does not include the costs of Medicaid-covered acute care services provided to waiver clients and ICF-MR clients. These costs are also provided on HCFA 372 reports. According to these data, ICF-MR recipients used an average of $2.09 in Medicaid-covered acute care services per day of institutional coverage, while waiver recipients used only an average of $0.45 per day for acute care services covered by Medicaid.

Given that ICF-MR recipients may be more medically involved than waiver recipients, these cost differences may reflect differing needs for medical care among the two populations. However, they may also reflect differences in access to medical care. For example, 42% of all ICF-MR recipients were provided physicians' services covered by Medicaid in the third waiver year, compared to just 22% of waiver recipients. At the same time, some waiver providers indicated during interviews that they had negotiated special contracts with health care providers to provide medical services to their waiver recipients. These contracts were paid for through the grants received from DDA under the waiver. Providers indicated that they had negotiated special contracts as a means of increasing access to medical services for their clients, given the generic problems of medical care access faced by all Medicaid beneficiaries in Maryland.

Data on the average cost per waiver recipient also masks considerable variation in costs across providers and clients. In FY 1988, the Medicaid waiver cost per client (excluding room and board) ranged from $22,502 per year to $41,292 per year. These variations in waiver client costs reflect the result of negotiated costs between providers and DDA. The major reason for these variations are differences in the service needs of the clients, although geographic variations in salary, housing, and other price inputs are also a factor. In general, providers who participated in the early phases of the waiver program had lower negotiated costs than those who entered the waiver program at a later date.

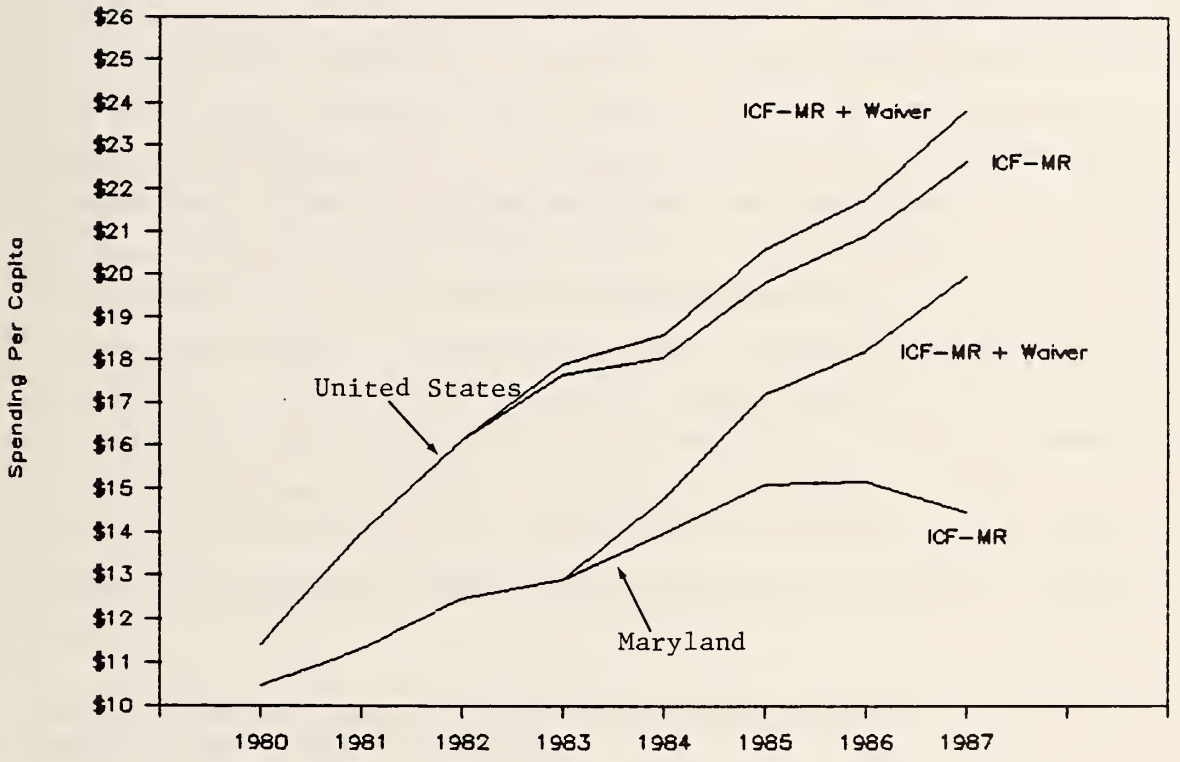
What impact has the DD waiver had on aggregate Medicaid spending for the developmentally disabled in Maryland?

Although the implementation of the DD waiver program was definitely associated with a decline in Medicaid expenditures for ICF-MR care, an additional research question is whether total Medicaid spending for MR/DD services have been positively impacted by the waiver program. This question is difficult to answer definitively because it requires evaluation methods to estimate what aggregate Medicaid spending for ICF-MR care would have been if the DD waiver program had not been implemented. One less definitive approach to addressing this question is simply to compare aggregate Medicaid spending per capita (ICF-MR plus waiver care) in Maryland to aggregate Medicaid spending per capita nationwide, since the implementation of the waiver.

These trends are presented in Exhibit 2-10. Although per capita spending for ICF-MR services in Maryland has clearly declined relative to per capita spending for ICF-MR services nationwide, waiver spending in Maryland has risen at a far greater rate than waiver spending in other States. Together, aggregate Medicaid spending in Maryland for MR/DD services is much closer in line to aggregate Medicaid spending for MR/DD services in the United States as a whole. Aggregate spending for Medicaid-covered services (ICF-MR plus waiver services) increased at an annual compound rate of growth of 11.5% in Maryland between 1983 and 1987, compared to 8.3% nationwide. Nonetheless, aggregate spending in Maryland was still significantly below the national average in 1987. In sum, Maryland has definitely increased its use of Medicaid as a financing mechanism for MR/DD services over the last five years, but it has done so through increased investment in community-based services under the waiver, rather than through increased investment in ICF-MR certified facilities.

Exhibit 2-10

Total Medicaid Spending Per Capita:
United States and Maryland



Spending per capita was calculated by dividing Medicaid expenditures by total U.S. or Maryland population. Source: HCFA 2082 data, Bureau of Data Management and Strategy (ICF-MR expenditures) and HCFA 64 data, Division of State Agency Financial Management.

Chapter 3

CURRENT ISSUES IN THE MARYLAND DD WAIVER PROGRAM

This chapter provides a brief discussion of some of the current program and policy issues in the Maryland DD Waiver program. Although the waiver program has clearly been successful in reducing the institutionalized population in Maryland, it has also had a major impact on the community-based service system. This expansion of the community-based service system in Maryland has created new problems in program management and service quality. Although HCFA is concerned with the cost-effectiveness of Medicaid waiver services in terms of the relative costs of waiver-funded services and ICF-MR care, it is also concerned with what it is buying in terms of standards of care on both sides of the equation. Relative to the ICF-MR program, waiver-funded services are less regulated and monitored by HCFA, but as Medicaid financing of community-based services continues to expand, it is clear that HCFA will become increasingly involved in ensuring that the services it is purchasing through home and community-based waiver programs meet appropriate and adequate standards of care.

What stresses have been placed on the community-based service system as a result of the DD waiver program?

The Maryland DD waiver program has put substantial stress on the community-based service system. Through both waiver and non-waiver community expansion, the community-based residential care system has almost doubled in size between 1983 and 1988, from about 1,400 residential clients, to over 2,700 clients. Day programs, transportation services, and other client support services have been forced to expand at a similar pace.

One strategy employed by the State in achieving this level of expansion was to support the establishment of new community-based providers. The State actively encouraged the development of new agencies, and was supportive of

individuals and groups who expressed a desire to start new agencies. Further, the resources were made available to help new provider agencies get started. Start-up money was available for new agencies to get residential programs up and operating, and the grant amounts available to serve waiver clients were more adequate than those for non-waiver clients. Whereas providers of non-waiver residential programs had traditionally had to rely on fund raising efforts to supplement inadequate reimbursement from the State, waiver providers were generally granted adequate funding to operate their programs without private funds.

One issue is the quality of the providers who got started under the waiver program. During the initial implementation of the waiver, the State was encouraging the establishment of new residential program providers to serve waiver clients. Also, some agencies which had, until then, operated relatively small programs, used the waiver as an opportunity to greatly expand their existing operations. Some respondents, generally those in the more established provider agencies, questioned whether some of these new agencies had the proper experience and credentials to expand so rapidly.

In conducting interviews, it appeared as if there were almost two separate camps of residential providers. On the one hand, there were the older, more established agencies, which generally had taken on only a few waiver clients, and who were more oriented towards the community-based population which had never been institutionalized. On the other hand, there were the relatively new providers who had become initially established, or who had grown very rapidly in recent years, due to expansions under the waiver.

Why didn't the existing providers participate more extensively in the waiver program? For one, existing providers had less of a need to expand--many were already very sizeable agencies--and second, many indicated that they were concerned with the impact which rapid expansion would have on the quality of their programs.

> "We know that there is absolutely no way you can take on 30 new clients and maintain program quality. It's difficult enough just getting one or two new ALUs going each year. Besides, the State wasn't courting existing providers. They wanted some new providers in the system."

On the other hand, some respondents indicated that existing providers were not that interested in serving waiver clients.

> "They [existing providers] are more oriented toward community clients. They're run by the parents on their boards, who are naturally more concerned with their own children. Institutionalized clients don't have that kind of advocacy. The State had to get some new providers if they were going to meet their quotas."

In sponsoring new providers under the waiver, there were a few disasters. One agency was unsuccessful in getting started, spent a lot of start-up money, and then folded. Another agency had to be brought in to take over their waiver caseload. In some cases, waiver clients had to be re-institutionalized or transferred to other agencies willing to take them. In another case, there was evidence of fraud on the part of a new provider agency prior to folding, which made the local papers. Other new providers, particularly those which expanded extremely rapidly under the waiver, have had continuing operational problems in terms of maintaining staff and meeting quality standards. On the other hand, there are success stories of new agencies being started by competent personnel who have worked extremely hard in developing new programs, and have met the challenge of providing quality services to a difficult population of clients.

One issue is whether the State could have moved more slowly in implementing the waiver, and developed the community-based system at a more conservative pace:

> "Moving more slowly was not an option. They [the State] had to meet the quotas set in the consent decree with the Justice Department. Getting these people out was obviously their first priority--quality was not their major concern."

Also, although there have been obvious problems associated with the rapid expansion of community-based providers over the short term, the State perceives the expanded supply of providers as ...."a godsend, that gives us a much broader base of providers with which to expand further. Moreover, it gave us the opportunity to develop more medium-sized providers that tend to operate more individualized programs. Many of the existing providers had gotten too large."

Furthermore, some thought the State should be given credit for accomplishing what they did in meeting their quotas.

"There are a lot of problems in the system, no doubt about it. But at least they got these people out of the institutions. No one should have to live at Rosewood. First, you get the programs going, then you worry about quality."

How are staffing problems affecting the quality of Medicaid waiver services?

If there was a single overriding issue in interviews with waiver program providers, it was the problem of recruiting and keeping direct care staff to work in residential programs. Many of the quality problems in the community care system relate to the problem of attracting and keeping direct care staff. Every provider had staffing vacancies. Providers indicated that the average direct care staff person stayed on the job only six months. High staff turnover at many providers has also increased costs due to the necessity of paying overtime for other staff to cover the residence.

The consensus among providers was that it was not possible to attract quality staff at the wages they could afford to pay. Most entry level staff earned between $4.50 and $5.50 per hour, or between $9,500 and $11,500 per year, although most earned more than that due to overtime.

> "The quality of our staff has definitely gone down over the last few years. Why should someone come to work with us for $5.00 per hour and have to work with difficult clients, when they can go flip hamburgers for $6.50? Plus, we're getting clients with more and more behavior problems, and the staff aren't prepared to handle them."

Respondents also referred to the "bad apples" in the system--people who have been fired by one agency for stealing, client abuse, or some other reason--and are immediately hired by another agency because they are so desperate for staff. In response, the licensing and certification division of DDA is developing a central registry of persons who have been accused of client abuse or neglect in DDA-operated programs. Before hiring new staff, providers will now be required to ensure that the new hire is not listed on this registry.

Since most providers received significantly higher reimbursement rates for waiver clients than they received for non-waiver clients, an obvious question was why they weren't able to raise salary levels in waiver-funded programs. There were generally two answers to this question. One was that it was not

possible to pay staff in a waiver home more than staff in a non-waiver home, for internal management reasons. Although waiver clients, on average, were more severely disabled than non-waiver clients, many clients in non-waiver homes were equally involved as waiver clients, so that higher salary levels in waiver homes could not be justified on the basis of more difficult clients. Second, providers claimed that DDA regulations for waiver-funded homes required more staff per home, and more supervisory staff, than non-waiver homes, so that higher reimbursement rates for waiver clients generally went to pay for more staff, rather than for more highly paid staff. Many waiver-funded ALUs had staffing patterns of two staff to three clients during waking hours, as opposed to one staff to three clients in many non-waiver homes. Further, in some homes, providers had to have awake staff in the residence at all times because clients required continual supervision and monitoring.

> "The screwball in the system is not the waiver program, it's the non-waiver side. You can't just raise salaries in the waiver program, it's got to be done systemwide."

Not all respondents believed staffing problems were just a matter of low wages. Some have tried to address the staffing issue through the use of alternative staffing patterns. Many try to be as flexible as possible in scheduling hours for residential program staff, so that staff can attend school or also work at other jobs. One provider has opted to use married couples as residential counselors. This provider believed that a married couple provided a more stable family environment for their clients, that married couples tended to be more stable in their own lives, and that this pattern allowed at least one spouse to supplement their income with another job.

In other cases, entirely different residential program models were being tried. One Director had started his agency with the idea of developing an entirely different approach to staffing residential programs.

> "I began this agency with the idea that our primary objective was to control turnover in staff. You can't provide quality services to developmentally disabled people unless the staff who work most directly with them every day are quality people. And you can't keep quality people unless you treat them right. We have a very flat organizational structure here--there's me, one residential program director, and then everybody else."

However, this provider was also able to benefit from a unique set of circumstances, not available to other agencies. The agency was affiliated with the Special Education department of a local State college, and exclusively used graduate students for residential program staff. The graduate students got free room and board, a salary, financial support for tuition, and also direct experience in the field of their degree. In return, the provider got direct care staff of high quality who had both an intellectual and professional interest in their jobs.

The other advantage of this model is that it combined direct care positions and supervisory positions into a single job. In most agencies, direct care staff report to supervisory staff who also handle the paperwork, who may report to residential program directors, who report to Executive Directors.

> "You know, the other day I was talking with the Director of another agency and he was bemoaning the fact that his direct care staff were so bad that he was going to have to hire three more supervisors. He's got it all wrong. He needs to figure out how to get better direct care staff, not hire more supervisors!"

The other program model that is being tried to address the staffing issue is the Individual Family Care (IFC) model, which is essentially a foster care model. In this model, providers sub-contract with individual families to take a waiver client into their home. This model has proven to be particularly effective in tapping a different, but appropriate, labor pool. IFC providers tend to be low-income, middle-aged women, many of whom are single, widowed, or divorced, whose own families have grown up and moved out of the house. Many have some background in the health care field as nurses or aides, and are typically nurturing-type people. Although they may live alone, most have large extended families who can provide back-up and respite. Although this model was only being used by a few providers, it was perceived positively as one solution to the labor supply problem for direct care staff. It was not considered an appropriate model for all types of waiver clients.

Other respondents expressed the belief that lack of training was another major factor contributing to high turnover rates among direct care staff.

Turnover among residential program staff is not attributable solely to low wages, but to the stresses of working with an increasingly difficult client population. Without training, staff are more fearful of clients, and do not know how to respond when clients are acting out. DDA has proposed that a training program be instituted in which new staff at community-based agencies would be trained at the SRCs before working in the community. This would allow new staff to observe how experienced staff at the SRCs work with clients. Given the very high turnover rates in community-based programs, there is very little transfer of knowledge from experienced staff to new staff. However, this proposal has never gotten off the ground.

Staffing problems have been exacerbated by very low increases in provider reimbursement rates over the last three years. In the first three years of the waiver, residential program rates were increased by only 4.5% in the first year, 2.5% in the second year, and 2.9% in the third year. All providers, once their initial grant is negotiated, receive the same increases. To specifically address the problems of low wages for direct care staff, the legislature approved $3.2 million for salary enhancements in FY 1988. Due to delays in calculating the most appropriate allocation method, however, these salary enhancement funds have yet to be distributed.

Respondents were generally pessimistic about any solution to the problem of high staff turnover in residential care programs. Although some alternative program models were being tried as ways of addressing the problem, most thought the problem would not be resolved without a significant increase in appropriations for community-based programs that could be translated into higher salaries for direct care workers. Better training, and better working environments, were also considered important factors in improving staff recruitment and retention in community-based programs.

To what extent are resources available to assist providers in serving clients with behavioral and/or medical needs?

Increasingly, clients served under the waiver are either behaviorally or medically involved, or both. A significant number have dual diagnoses of mental illness and mental retardation. Some clients are incontinent, some display inappropriate sexual behavior, some become physically aggressive when

stressed, and others run away at every opportunity they get. Many providers stated that they did not expect the level or intensity of behaviors exhibited by their waiver clients. Although most all providers had interviewed prospective waiver clients while they were still at the SRCs, and had reviewed their records, many claimed that the level of behaviors was more severe than originally anticipated. Some respondents went so far as to claim that the State and the SRCs had placed the more difficult clients on the waiver placement list, rather than those who were most appropriate for community placement.

Almost all respondents stated that the support services needed to develop effective behavioral management programs for waiver clients, and to provide crisis intervention services, were woefully inadequate. To provide behavioral management support for waiver clients, the State has developed a multi-tiered approach. First, all waiver providers are given funds for "Consultants' Fees" in their annual grants. These funds may be used to purchase behavioral management services on an as-needed basis. However, these fees are also used to purchase other professional services for waiver clients, including physical, speech, and occupational therapies, and sometimes medical care that is not reimbursable under the regular Medicaid program. Providers indicated that these budgets were not sufficient for purchasing the level of services actually required by their clients.

Second, the State has developed an Intensive Behavior Management Program (IBMP) which consists of special IBMP units in each of the four Maryland regions to provide consultant support services and short-term in-patient back-up to community-based providers. A different model is employed in each region. However, providers must purchase services from the IBMPs with the resources available through their grant. While providers were generally positive about the quality of services available, they also stated that the price of the services was expensive, and therefore not routinely available to all clients.

Third, DDA had intended to use the Carter Center, an 8-bed facility attached to the University of Maryland at Baltimore, as a more long-term in-patient resource to provide intensive behavior management for specific

clients. The Department had been forced to use the facility as a locked facility for criminally dangerous patients, and had never been able to make this resource available. However, resources have been approved by the legislature to free up these beds in FY 1989, and to make it an available resource to community-based providers within the next year. In fact, DDA sought and obtained legislative approval to substantially expand its behavioral management support services in FY 1989.

Providers' opinions about the effectiveness of behavioral management support services were not uniform. The availability of resources varied from region to region. Although the resources which were available were viewed positively for the most part, the greater concern was about access and cost. Some also thought that the services were not appropriate to the need.

> "I don't need some Ph.D. to come out here and write up a [behavior management] plan that is way over the head of my staff. I need something simple, that works, and that my staff can implement."

Other respondents felt that the reliance on an externally-structured behavioral management system was the wrong approach.

> "If you're going to do it right, you've got to do it yourself. People from the outside just don't know the client well enough. Plus, the services need to be rendered at the place where the problem is occurring. We had a client who was always running away, so we sent her to the IBMP. Their response was to put her into a locked ward!"

Further, providers said it was very difficult to admit clients for in-patient services.

> "Everybody acts like it's our problem. Their attitude is to 'hang in there' and deal with it ourselves. They're afraid that we're trying to dump our clients back on them, when we're not. They're not assisting us with keeping people in the community; their attitude is to <u>make</u> you keep people in the community."

In general, providers expressed a desire to simply make more resources available for developing behavioral management programs within the agency itself, rather than having to rely on accessing external resources. More

emphasis should be placed on identifying potential behavior problems before they occur, and developing plans for preventing those behaviors from occurring in the first place. However, they also expressed a desire for more in-patient back-up when things get totally out of control.

Some providers also have difficulty obtaining access to generic health care services for their waiver clients. This problem was perceived as a general problem of Medicaid beneficiaries, not specific to the waiver program. A number of providers had also experienced particular difficulties related to the characteristics of their clients. "The hospitals always think that we're trying to dump our clients on them, and try to discharge them as soon as possible." Many providers use walk-in clinics as their primary source of medical care, but many expressed a desire to develop more permanent relationships with physicians who would get to know their clients better, and who could provide more continuing care. As previously discussed, a few providers had negotiated special contracts with local providers, such as HMOs, to provide ongoing care to their waiver clients for services that were not reimbursable under Medicaid.

How effective are the quality assurance mechanisms employed in the waiver program?

As previously discussed, Maryland uses a multi-tiered quality assurance system in the Medicaid waiver. There are four major components in the system. First, all residential program providers must be licensed by DDA. Licensure and certification teams from DDA inspect residential care providers annually to monitor compliance with DDA regulations for DDA-funded clients and programs. Second, since waiver providers are also Medicaid-certified providers, the Medical Assistance Compliance Administration of the State Medicaid agency conducts annual reviews of waiver clients to ensure compliance with Medicaid regulations on the waiver program. Third, DDA contracts with a private organization, the Delmarva Foundation, Inc., to conduct annual re-certifications of waiver clients to determine their continuing eligibility for waiver services.[1] The Delmarva Foundation continued stay review also

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[1]Under Federal regulations, developmentally disabled persons receiving waiver services must meet ICF-MR Level of Care criteria at admission to the waiver, and at annual re-certifications. If waiver clients no longer meet criteria for placement in an ICF-MR certified facility, then they are no longer eligible for waiver services.

includes a quality assurance component. The reviewers evaluate whether clients receive updated assessments of needs in 13 service domains, whether the assessed needs are being met by qualified staff, and whether needs are being periodically re-evaluated. Fourth, Service Coordinators are responsible for developing and revising the client's Individual Service Plan (ISP), for coordinating and monitoring the services identified in the ISP, and for maximizing access to services in the community that are not covered under the waiver. Service Coordination is financed as a waiver service, and in the third year of the waiver (1986-87), $583,582 out of the total of $13,515,339 in waiver expenditures (4.3%) were for Service Coordination.

In addition to these four basic components of the quality assurance system, most providers are subject to additional monitoring by their Regional DDA offices and by their county health and fire departments. Given this multi-tiered system of external monitoring of waiver clients and providers, the issue is whether the system is effective in ensuring that waiver clients are receiving quality services under the waiver.

While respondents acknowledged the need for external monitoring of community-based providers, there was common agreement that the current quality assurance system was not doing a good job of promoting quality. A major criticism was that external monitors, well intentioned or not, simply did not know clients well enough to make professional judgements about the quality of care that clients were receiving. It was frequently recommended that the State pool the resources that are currently spent on a multi-tiered system, and invest it in a quality assurance system in which professional monitors could spend more time getting to know individual clients on a personal basis, and advocating for services on the client's behalf on the basis of that familiarity. Because quality assurance resources were spread across a wide range of activities, it was felt that no single activity was sufficiently funded to do the job correctly. DDA licensing teams were so overburdened with the demands of community expansion that they were considerably behind in conducting annual licensing reviews. Similarly, some believed the Service Coordination component of the waiver had never been sufficiently funded to hire the kind of professional staff who knew how the MR/DD system worked, so that they could effectively access services on clients' behalf.

A second criticism of the quality assurance system was that it focused too much on the details, rather than on the overall quality of life of the client.

> "The people at DDA all came out of the institutions, and they manage community programs just like they were institutions. The regulations look at all the details, but they don't reflect the client's quality of life. Everyone's concerned with how many washcloths are in the bathroom, or that someone's bedroom isn't right off the kitchen, but no one asks when was the last time Jim had a date, or a vacation, or if he likes his job. Someone could ace all the regulations and still have a miserable life. Likewise, someone could have a great quality of life, but be totally out of compliance with the regs."

A third criticism of the system was that the system was totally oriented towards identifying problems, but was not at all helpful in proposing solutions.

> "The last thing in the world we need is someone else coming in here to tell us our problems. We know our problems well enough. We'd like the State to be a little more supportive in helping us come up with some solutions, not just tell us what we're doing wrong."

Even those involved in quality assurance activities agreed that the system had become somewhat negatively oriented.

> "There were obvious quality problems with community expansion, and the State's response has been to increase restrictiveness. They put many controls on the system in order to get quality. And the controls focused on pickier and pickier things. I think the whole system has lost something in the process. It has killed creativity. People are also losing their enthusiasm."

A related criticism was the explosion of paperwork that accompanied the increase in monitoring and quality assurance activities under the waiver. Although providers recognized the need to document the services they were providing, there was concern that the emphasis on paperwork was detracting, rather than contributing, to quality of care.

> "The whole system has been designed around Medicaid, and Medicaid has just made it worse. When that's [paperwork] what you get checked on, then that's what you spend your time on. I think we've learned that more paperwork isn't accomplishing anything. Anybody who's up on their paperwork probably isn't working with clients properly. But it's hard to go back and say we don't need this much paperwork."

Of all the components of the quality assurance system, Service Coordination was the most controversial. Providers thought the Service Coordinators' role had never been clearly defined. There was particular confusion over whether Service Coordinators were primarily client advocates or service facilitators. Providers indicated that the contribution of Service Coordinators varied widely from individual to individual. Some providers felt that their Service Coordinators had made a positive contribution to client care; others thought that the entire Service Coordination component was a total waste of resources that would be better invested elsewhere in the system. Service Coordinators themselves agreed that their role in the system had not been well defined, and that their role often had to be "individually negotiated with each provider."

In comparison to Service Coordinators (case managers) in other Medicaid waiver programs for the developmentally disabled, Service Coordinators in Maryland have a more limited role. Case managers in other waiver programs often conduct initial assessments of clients to determine eligibility for the waiver program; have authority over the types and volume of services included in the Plan of Care (and thus the payment amount per waiver client); conduct annual re-certifications of client eligibility and revisions to the Plan of Care; and are the lead monitor of waiver program providers. A key difference in Maryland is that the client's Individual Service Plan (ISP) developed by the Service Coordinator has no administrative or financial link to the reimbursement amount for the waiver client negotiated by DDA, although the reimbursement amount is at least theoretically linked to the service needs of the client.

What are the future prospects for the waiver program over the next few years?

There was considerable uncertainty among respondents about the future direction of the Medicaid waiver program. The consensus was that the rapid community expansion that had occurred over the last four years had put "considerable stress on the system," and that the State needed to "shore up the service delivery system" before expanding further. "Shoring up the delivery system" was often in reference to the need to improve behavior management programs and crisis intervention programs for challenging clients before

placing more clients into the community. It was also felt that the supply of day program services had not kept up with the expansion of residential programs, and that the next phase of community placements under the waiver should be preceded by placements into day programs.

Many of the providers indicated that they were not planning to bid in the next round of RFPs for new waiver clients. Of those who were, most indicated that they would expand more conservatively this time around, perhaps developing one or two more ALUs at the most. They also intended to do a more thorough job of screening the clients they bid on, given their experience in the first rounds of waiver placements. "The clients still living at the SRCs are not going to be easy to serve. It's getting to the point where nobody wants to take any more clients."

There was particular concern about the impact of further community placements on the supply of labor for direct care staff. Given the high number of vacancies in existing residential programs, providers were concerned about the impact of further increases in the demand for labor without some prospect for increasing salary levels for staff. A number of respondents indicated that their neighborhoods, particularly low-income neighborhoods, were getting saturated with community-based residential programs of all types--mental health, drug abuse, juvenile offenders, as well as programs for the mentally retarded. Some were concerned about political backlash from their communities due to over-saturation.

Another concern of the more experienced providers was the lack of management experience in the system. "The whole system is being run by first-time managers." More training for management as well as staff was considered a critical element in the further development of the system.

At the same time, respondents agreed that there would "always be providers willing to bid on new clients." The implication was that the providers who were more concerned about quality would be more conservative in expanding further, while those less concerned with quality would continue to pursue a strategy of high growth. Also, some respondents felt that given the low rate of inflationary increases granted by the State over the last few years, that

some of the smaller providers would have to grow "just to keep their heads above water."

Respondents also felt that there had to be a balance between further growth in the waiver program and growth in non-waiver residential program placements. It was felt that parents with severely disabled children graduating from special education programs deserved equal access to community residential placements for their children as clients served at the SRCs. Some providers felt that they could only get support from their Boards to expand their waiver programs if they also expanded their non-waiver residential programs as well. Thus, the future growth of the waiver is going to be inextricably linked to the development of non-waiver residential programs. In the FY 1989 budget, the Maryland legislature has approved 100 more residential placements for non-waiver clients (at an annualized cost of $2.6 million) in addition to the expansion of 160 new waiver placements (at an annualized cost of $7.2 million, half to be paid by the Federal government).

The State is projecting substantial increases in the cost of serving waiver clients. Given the low demand for new clients by providers, and the higher service needs of clients awaiting placement, the State is projecting an average annual cost of $44,962 for the next 160 clients to be placed in the waiver. This cost will not be the same as the average Medicaid waiver cost per client because it includes room and board and other costs that cannot be claimed under the waiver.[2] This average annual cost in what will be the fifth year of the Medicaid waiver is 28% higher than the average annual cost per recipient reported in the third year of the waiver. However, the average annual cost for all waiver recipients served in FY 1989 will be less than $44,962 since the costs of clients placed in FY 1989 will be averaged with those placed in earlier years, at a much lower cost.

As the cost of serving waiver clients continues to increase, one question is whether the waiver program will continue to meet the test of

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[2] If we assume that 10% of the annual cost for waiver clients is not recoverable under the waiver, then the average annual cost to Medicaid would total $40,466. Both figures also exclude SSI payments made to providers by waiver clients, which will average about $3,100 in FY 1989.

cost-effectiveness. In other words, will it eventually be more expensive to serve waiver clients in the community than in the SRCs? However, one irony of the "cost-effectiveness" test in the Medicaid waiver program is that placement of institutional clients into the community has the additional effect of driving up average client costs in the institutions, as the fixed costs of operating the institutions get spread over fewer clients, as discussed in Chapter 2. For example, the annual average cost per residential care bed at the Rosewood Center (which is not quite the same as cost per recipient) has increased from $38,341 to $65,493 since FY 1985.

Despite the many problems cited by respondents concerning the expansion of community programs and the implementation of the Medicaid waiver, most respondents were quite positive about the overall impacts of the Medicaid waiver program. While they acknowledged there was a long way to go in developing a community-based services system that provided quality services, many respondents gave the State credit for achieving their deinstitutionalization objectives. Many thought that problems in quality were inevitable, given the limited capacity of the community-based service system at the time the waiver was implemented, and the need to use the waiver to develop a broader community-based service system infrastructure. Many thought that the most important point was that waiver clients had gotten out of the institutions, and that no matter what, the quality of life for most of them had improved considerably in the community. Many commended the State for sticking with a program model of three clients per residence (despite its higher cost), since they felt that small program models were more normalizing than large program models. Finally, several respondents observed that it was unrealistic to expect for system infrastructure to precede community expansion, because "services always follow clients, not vice versa."